Maine Newborn Hearing Program Advisory Board

Senator Inn & Conference Center, Augusta, Maine

Date: May 1, 2009 12:00 to 4:00

Members Present: Eileen Peterson, Louise Packness, Karen Hopkins, Romy Spitz,

Kristen Shorey, Karen Harrison, Cindy Brown, Carrie Chojnowski,

Lisa Sockabasin, Jennifer Libby

Members Absent: Brenda Medlin, Harriet Gray, Deb Stroud, Karen Perry,

Annette Bowman

Program Staff: Betsy Glencross, Ana Scovil, Jim Dean, Vivian Mikhail

Presenter: Janet Farrell

Moderator: Betsy Glencross

Scribe: Ana Scovil

I. Please update contact information with Ana

II. Approval of minutes from: February 11th, 2009, accepted.

III. Program Updates: Betsy Glencross

- Betsy and 4 others from Maine attended the 2009 EHDI conference. They
 began the development of a State action plan on which the board will also
 work. Those who attended are scheduled to have follow-up meetings
 throughout the year.
- o Betsy, Toni and Brenda Medlin agreed to meet to clarify and further develop the Chapter Champion role.
- MNHP Data was presented to Maternal Child Health Block Grant writers in April and was included in the meeting packet.
 - This is the first year we are able to report "Data of Diagnosed with hearing loss, MNHP received data on enrollment in Part C Early Intervention"
 - Data of "MNHP received audiological report" has increased with assistance from Eileen sending out e-mails to the Maine Academy of Audiology members, our parent consultant following-up with families, Pattie Chasse contacting PCPS, Jim Dean's audiology consultant work and a full team effort. We are continuing to refine our follow-up efforts.

o 1-3-6 Process

- Betsy, Toni, Vivian and Ana had a meeting to develop a better way to deal with our lost to follow-up process.
- Betsy is attending the Perinatal Nurse Managers Meeting in June to discuss newborn hearing process & concerns. Betsy will update the Board at our next meeting
- A ChildLINK & Epidemiology meeting on evaluating and analyzing data and doing more refinement was held in April.

- 2009 Audiology Evaluation Facilities for Infants listing has been distributed to CDS, ECFS and will be mailed out to physicians, birth facilities, audiologists and other providers.
- CDS state-wide referral process is being worked on. Betsy and Jim are scheduled to attend upcoming CDS "Lunch & Learn" sessions to discuss MNHP with CDS sites.
- ChildLINK Evaluation Stakeholder Meeting: looking for a broad range of stakeholders in the evaluation process of surveillance system, ChildLINK. The evaluation process will take a year it will address different parts of the system including public health importance, purpose, operation, resources used and performance. Stakeholders will be asked to attend two in-person meetings and to provide input via email. To participate please contact Betsy.
- NICHQ (National Initiative for Children's Healthcare Quality) we were approved by the State on April 3rd to participate. Current team members are Vivian, Jim, Toni and Betsy, more will be added soon.
- o Jim Dean is not renewing his audiology consultant contract as he is moving to AZ. We are advertising for applicants.

IV. Audiology Consultant Overview/Update: Jim Dean

- Developments on increased awareness and increased communication with agencies will continue to improve with MNHP, CDS, and MAA (Maine Academy of Audiology).
- o 2009 Maine Pediatric Audiology Guidelines *DRAFT* was included in the meeting packets. Jim would like to hear comments from the board. Guidelines will include the new process for referring to CDS with one main number. Please look over the substance of the guidelines and submit your comments no later than May 15th to <u>Betsy</u>.
- Outreach was being worked in rural communities, Native American populations, and underserved minorities. Suggest that the new audiology consultant consider outreach to Somalis, Hispanics and other groups.
- ChildLINK database has modified the reporting data. The System is being updated daily as we are now getting more audiologist reports. Betsy should now be able to report to CDS in a timelier manner.
- Auditory Neuropathy Dys-synchrony is now being called ANSD (auditory neuropathy spectrum disorder) and a new tri-fold brochure is being developed to provide education on this.

V. Parent Consultant Update: Vivian Mikhail

- Attended the March 2009 EHDI conference and will report from the follow-up meeting that is coming up.
- Birthing facilities Referral forms are being received by MNHP prior to receiving birth certificate data and we are obtaining information that is being forwarded to the parent consultant to follow-up with families for early and direct contact.

- May 19th meeting with the Betsy, Karen, and Lynn to gather documentation on further defining the parent consultant's role. Example: Data on how many families with have been contacted successfully, etc.
- Hands & Voices Maine:
 - A family Fun day at Camp Capella will be held on July 25, for all families with children who have hearing loss. MNHP will help sponsor this.
 - Looking for board members to join Maine Chapter Hands & Voicesplease contact <u>Vivian</u> if interested. An application form was included in the meeting packet.

VI. Action Items from Previous Meeting

- Subcommittee Reports:
 - Specialty Provider: Romy Spitz
 Database has been created and pending resolution with Toni Wall.
 - Membership: Kristen Shorey
 - We have a parent that is interested in filling the seat Parent of Culturally Deaf Child. The seat of a Culturally Deaf person continues to be vacant. Matt Hearst who is an ENT has expressed interest on the board although we have not received any paper work he would fill an "other" seat as there is no defined seat for an ENT.
 - Betsy will follow-up with the Governor's office to see Jen Libby has been appointed yet
 - Presentation: Louise Packness
 - May 7th Presentation to the Maine Speech and Language Hearing Association spring conference the focus for the presentation is to promote interest for more providers to work with babies (children under 3).
- o Cultural Competency: Romy Spitz / Lisa Sockabasin
 - Medical Interpreter will be educated and trained.
- o Training Module for Birth Facilities: Betsy
 - Betsy is working on the training module. More ideas are progressing on making it a more comprehensive module. Will have more information after the Perinatal Nurse Managers meeting in June.
- Prenatal Brochure- We want to develop a brochure targeting families prior to birth with the intention to distribute this to OB/GYN offices, midwives, prenatal classes, etc. Ana will research what other states might have and report at our next meeting.
- o 2009 EHDI Conference follow-up: Jim, Vivian, & Betsy
 - Jim: The EHDI Conference raised a couple of topics that audiologists should address. One is that NICU babies that are often being missed and second the risk factors for identification of delay onset hearing loss.

- Audiologists need to make parents aware of the **importance** of followup.
- Vivian: Having parents report is going forward for quality support and follow-up
- A Sample Hearing Loss brochure for families that NCHAM will provide to us was included in the meeting packet. NCHAM will also allow us to have an insert with our state resources. Looking for feedback on; do we want to use it; how the board would like to use it? E-mail feedback to Betsy by May 15th

VI. Presentation: Janet Farrell, NCHAM Liaison and MA EHDI Coordinator

- Janet gave the Board an overview of:
 - 1-3-6 Process with emphasis on '6'. Background/ Overview and National Perspective; what can we learn from Massachusetts?
 - Planning for Maine
 - Janet's Power point presentation is available upon request and handouts were included in the meeting packet.

VII. NICHQ (National Initiative for Children's Healthcare Quality)

- Janet gave an overview of NICHQ, What we can learn from Massachusetts?
 NICHQ process.
- o Our draft AIM Statement, (Identifying what we will work on with our learning collaborative) was included in the meeting packet.
 - We hope to partner with Eastern Maine Medical Center.
- $\circ~$ Toni, Betsy, Vivian, and Jim are going to the 1^{ST} session in Atlanta, May 11-13.

VIII. State Action Plan

- The draft State Action Plan was included in your meeting packet. You may email input to <u>Betsy</u>.
- **IX. Networking/ Sharing Info** Romy: Deaf Services Conference June 26 at Colby College in Waterville FREE CONFERENCE.
 - o Hand & Voices SAVE THE DATE July 25th Family Fun day at Camp Capella.
 - Next Steps planning team requests input from the Board for workshop topics.
 The next conference will be Nov. 12th and 13th in MA. Karen Hopkins and Louise Packness are on the planning team.
 - Maine Speech Language Hearing Association Spring Conference May 6th, 7th and 8th

X. Wrap up/ Plan for Next Meeting

Please submit any topic for next meeting no later than August 23, 2009.

XI. Next meeting:

Sept 23rd 12-4 at the Senator Inn & Conference Center Election for Board co-chair will be held at this meeting.